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FACULDADE DE PSICOLOGIA

"Sexual and Reproductive Health in Type 1 Diabetes Mellitus":

An Exploratory Approach to Emerging Adults' Perceptions

Ana Rita Nunes dos Santos

MESTRADO INTEGRADO EM PSICOLOGIA

(Secção de Psicologia Clínica e da Saúde – Núcleo de Psicologia da Saúde e da Doença)

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Dissertação orientada pela Professora Doutora Patrícia Pascoal e coorientada pela

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RESUMO

A Diabetes Mellitus (DM) é uma das doenças crónicas com maior incidência e prevalência a nível mundial. Entre os diferentes tipos de diabetes, a Diabetes Mellitus Tipo 1 (DMT1) é a forma de diabetes que, na grande maioria dos casos, é diagnosticada antes da entrada na idade adulta e que acompanha o indivíduo ao longo de toda a sua vida. A longo-prazo, a DMT1, aliada ao avançar da idade, ao número de anos de diagnóstico e a um controlo glicémico desadequado, pode desencadear o aparecimento de complicações, entre as quais problemas ao nível da saúde sexual e/ou reprodutiva.

O período de transição da adolescência para a entrada na vida adulta é caracterizado por marcos desenvolvimentistas ao nível da sexualidade, exploração da identidade, independência financeira, formação de vínculos afetivos e sexuais que tendem a ser mais estáveis e da tomada de decisões face a planos de vida futuros. No curso do desenvolvimento humano, o aparecimento de uma doença crónica, constitui por si só um fator que tem impacto em diferentes áreas do desenvolvimento individual, desencadeando períodos de crise que podem interferir com as tarefas de desenvolvimento normativas desta fase da vida. Neste sentido, os adultos emergentes com DMT1 enfrentam exigências adicionais associadas à gestão da sua condição de saúde crónica e ao aparecimento das possíveis complicações a longo-prazo.

De acordo com os modelos da Psicologia da Saúde, a forma como um indivíduo perceciona e representa, tanto a doença como os desafios que esta impõe vai determinar as suas respostas e comportamentos de saúde, interferindo com o seu bem-estar, qualidade de vida e processo de desenvolvimento global adaptativo. A conjugação de conhecimentos destes dois domínios de investigação, Psicologia do Desenvolvimento e da Saúde, cria os pressupostos teóricos que sustentam a necessidade de explorar se a sexualidade e a função sexual são, ou não, afetadas pelas perceções e experiências da DMT1, numa fase da vida que envolve inúmeras transições sociais. Assim, para além dos

estudos que têm sido desenvolvidos para compreender o efeito da componente biológica da DMT1 no funcionamento sexual, interessa explorar as implicações psicológicas e interpessoais que problemas ao nível da saúde sexual e reprodutiva podem despoletar nos adultos emergentes, bem como nas suas relações românticas. A escassez de literatura que explore o desenvolvimento social e sexual de adultos emergentes com DMT1, não permite compreender as perceções, expectativas e experiências face à relação entre a vivência com a doença crónica e a experiência da sexualidade num período-chave de transição, como é a entrada na vida adulta.

A presente investigação surge, assim, com o objetivo de contribuir de forma significativa, ainda que preliminar e modesta, para a compreensão de aspetos pouco explorados face à vivência e perceção das relações românticas e da saúde sexual e reprodutiva por parte de adultos emergentes com DMT1, dando-lhes voz no que diz respeito às suas expectativas e experiências a estes níveis, de forma a proporcionar aos profissionais de saúde e à comunidade um maior conhecimento sobre a forma como vivem as relações românticas, a sexualidade e a vida reprodutiva.

De forma a alcançar os objetivos propostos foi desenvolvido um estudo exploratório qualitativo, com uma amostra de adultos emergentes (n = 59), com idades entre os 18 e os 35 anos (M = 26,66, DP = 4,74), que falam Português e com diagnóstico de DMT1. Os participantes responderam a um questionário online com três questões de resposta aberta. A estrutura das questões progride de um espetro mais global de abordagem ao tema, para questões mais específicas da experiência dos adultos emergentes com DMT1 no que diz respeito à sua saúde sexual e reprodutiva. Assim, considerando a literatura, que dá relevância ao impacto da doença crónica nas relações românticas de adultos emergentes, a primeira pergunta procura identificar as perceções desta população relativamente ao impacto da DMT1 na formação de relações românticas. A segunda questão procura, de forma mais específica, explorar dúvidas e/ou questões dos

participantes face à sua saúde sexual e reprodutiva. Por último, a terceira questão remete para a exploração da experiência de dificuldades ao nível da saúde sexual e/ou reprodutiva, procurando identificar estratégias de respostas às quais os adultos emergentes recorrem para lidar com as mesmas.

A abordagem metodológica para a análise das respostas dos participantes a cada questão foi realizada com recurso ao QSR NVivo Pro 11, através do processo de análise temática, e resultou num conjunto de temas, subtemas e códigos que foram organizados em três sistemas hierárquicos diferentes.

Considerando a natureza exploratória do estudo e os objetivos propostos, embora um grande número de participantes não tenha identificado desafios específicos ou dificuldades experienciadas na sua vida sexual e/ou reprodutiva, quase todos mencionaram questões e/ou dúvidas e experiências relacionadas com este tema. Com base na análise de resultados foram identificadas dois temas representativos dos desafios específicos expressos pelos participantes: *Impacto Intrapessoal* (ex.: *gestão das próprias expectativas, adaptação ao diagnóstico* e *autorevelação*) e *Interpessoal* (ex.: *compreensão por parte do parceiro, hiper e hipoglicémias* e os *conhecimentos do parceiro* face à doença, à sua gestão e às possíveis consequências). Embora apresentados de forma separada, estes temas estão interrelacionados, partilhando o subtema *impacto na saúde sexual e reprodutiva*, também identificado como um desafio específico desta população. No que concerne às questões e/ou dúvidas identificadas pelos adultos emergentes, surgem preocupações face à *resposta sexual*, à *resposta metabólica do organismo à doença* e a todo o *processo de planeamento familiar*, desde a pré conceção ao nascimento. Por fim, as dificuldades experienciadas pelos participantes surgem ao nível da *atividade sexual*, *alterações orgânicas a nível urogenital* e *reprodutivo* e *experiência emocional negativa*, que aparecem associadas a *Processos Intrapessoais* (ex.: evitamento e correção da hipoglicemia) e *Interpessoais* (ex.: compreensão do parceiro e

comunicação com este) de resposta às mesmas por parte dos adultos emergentes com DMT1.

Vistos como um todo, os resultados obtidos demonstram que as relações românticas e a saúde sexual e reprodutiva constituem uma fonte de desafios, dúvidas e experiências expressas por adultos emergentes com DMT1. A possibilidade de ocorrência de *hipo e hiperglicemias* durante o ato sexual surge como um dado crucial identificado, que emerge como uma temática relevante nas três questões analisadas e associada a estratégias de resposta. Por outro lado, para além das questões orgânicas mencionadas, existe um conjunto de processos psicológicos que os adultos emergentes identificam como específicos e relacionados com a vivência da sua doença crónica ao nível da saúde sexual e reprodutiva. Adicionalmente, parece também existir um reportório de estratégias às quais os adultos emergentes com DMT1 recorrem para lidar com possíveis dificuldades sentidas, o que demonstra uma capacidade de adaptação face a aspetos que são considerados desafios específicos e estão muitas vezes associados a dúvidas e/ou questões identificadas por esta população.

Globalmente, o conjunto de dados recolhidos neste projeto de dissertação chama a atenção para a importância da abordagem de temas da saúde sexual e reprodutiva em contextos clínicos e sociais e, como tal, realça a importância desta área como parte constituinte da formação de profissionais de saúde. Neste sentido, o presente estudo inicia uma linha de investigação que deve ser tida em conta e explorada em projetos futuros, realçando não só o papel central das relações românticas na promoção da saúde e no bem-estar dos indivíduos mas também a necessidade de modelos diádicos de investigação.

Palavras-chave: Diabetes Mellitus Tipo 1, Saúde sexual e reprodutiva, Adultos emergentes, Análise temática, Relações românticas.

ABSTRACT

Type 1 Diabetes Mellitus (T1DM) is one of the most prevalent chronic conditions in the world and is associated with the development of long-term complications such as sexual and/or reproductive health problems. However, research exploring this topic among T1DM emerging adults has been scarce. This study seeks to explore the perceptions of T1DM emerging adults regarding the impact T1DM has when establishing romantic relationships, the specific challenges, concerns and/or experienced difficulties regarding their sexual and reproductive health, as well as their responses and strategies in dealing with these issues as they occur. We present a thematic analysis of the answers to three open questions of an online qualitative exploratory survey. The participants (n = 59) were emerging adults (ages 18-35), who speak Portuguese and have a T1DM diagnosis. Our results highlight that sexual and reproductive health are important themes identified, with an impact on a personal and interpersonal level. The specific challenges reported are related with the uncertainties and difficulties experienced, mainly regarding sexual and reproductive health as well as associated organic behaviors. Hypoglycemia and hyperglycemia during the sexual activity, especially sexual intercourse, suggests a novel data that is identified as a challenge, a doubt and an experienced difficulty, but that was also associated to specific response strategies. The findings emphasize the importance of research on sexual and reproductive health among the population of T1DM emerging adults. In particular, it is essential to give more attention to the multidisciplinary approach to this population needs and to the bidirectional influence of social relationships on health, especially the role of romantic partners in promoting their partners' health and well-being.

Key words: Type 1 Diabetes Mellitus, Sexual and reproductive health, Emerging adults, Thematic analyses, Romantic relationships.

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1. INTRODUCTION

Type 1 Diabetes Mellitus (T1DM)[1] is usually diagnosed during childhood, adolescence and emerging adulthood. It is recognized as a serious public health problem worldwide due to its increasing incidence and prevalence, as well as due to the development of long-term complications (American Diabetes Association [ADA], 2014; Craig et al., 2014). Sexual health problems are one of these complications (ADA, 2014), and although some studies have been developed in order to understand the biological component associated with the long-term impact of this chronic disease in sexual functioning, it is important to consider the psychological and interpersonal implications that this condition can cause in the sexual health of an emerging adult.

The research on T1DM has predominantly focused on adolescence (Helgeson, Snyder, Escobar, Siminerio & Becker, 2007; Karlsson, Arman & Wikblad, 2008); however, it is in the transition from adolescence to adulthood that the complications of diabetes begin to manifest (Bryden, Dunger, Mayou, Peveler & Neil, 2003). Moreover, it is also in this age frame that there are innumerable normative changes in the sexual development of emerging adults, such as the intensification of the identification as a sexual being, the recognition of sexual orientation, the reconciliation with sexual arousal, and the formation of romantic and sexual attachments (Halpern & Kaestle, 2014). From the Health Psychology perspective, perceptions about illness progression are also important to understand, because these guide disease management decisions and may affect adherence and psychosocial adjustment, as well as interfere with the well-being and adaptive global development process of individuals (Fortenberry et al., 2014; Law, Tolgyesi & Howard, 2014; Sawyer, Drew, Yeo & Britto, 2007). In this sense, the process by which sexual function and sexuality are affected by T1DM can have a negative

[1] In this paper, the acronym DM refers to Diabetes Mellitus in general and T1DM specifies Type 1 Diabetes Mellitus.

psychological impact on emerging adults and on their relationships, already burdened by the presence of the chronic disease (Sawyer et al., 2007; Verschuren, Enzlin, Dijkstra, Geertzen & Dekker, 2010). It seems especially important to understand how living with a chronic condition such as T1DM, in this key transition period of life, interconnects with the experience of sexuality, namely the formation of expectations and actual experiences. However, our review of the literature did not find any studies exploring the sexual development and the reproductive life of emerging adults with T1DM, so we do not know if there are any specific issues in the sexual and reproductive life of this age group. Obtaining this knowledge would allow to better inform health practitioners and increase public and social awareness about the experiences of emerging adults with T1DM. The current study aims at helping to fill this gap in the existing research by giving voice to emergent adults with T1DM concerning their romantic, sexual and reproductive expectancies and experiences.

2. REVIEW OF THE LITERATURE

2.1. Type 1 Diabetes Mellitus (T1DM)

According to the American Diabetes Association (ADA, 2014), Diabetes Mellitus (DM) is a complex and systemic metabolic disorder, which affects both sexes, all ages and constitute one of the most prevalence chronic conditions in the world. DM is characterized by chronic hyperglycemia resulting from defects in insulin secretion, insulin action or both, which leads to abnormalities of carbohydrate, fat, and protein metabolism (ADA, 2014; Craig, et al., 2014).

Most cases of DM can be classified into two broad etiopathogenetic categories: T1DM and type 2 Diabetes Mellitus (T2DM) (ADA, 2014). The present paper will only focus on T1DM, which is characterized by chronic autoimmune destruction of pancreatic β-cells that occurs at a variable rate, leading to absolute or partial insulin deficiency and consequently leads to daily dependence of exogenous insulin administration (ADA, 2014; Craig et. al., 2014). The chronic hyperglycemia of T1DM presents a potential risk factor for the development of long-term complications, such as macro and/or microvascular diseases, retinopathy, neuropathy and impairments in sexual function (ADA, 2014), which can occur 5 or 10 years after the diagnosis (Ziaei-Rad, Vahdaninia & Montazeri, 2010).

Considering the data from the Portuguese National Observatory of Diabetes (Gardete Correia et. al., 2016), T1DM is usually diagnosed at a young age (e.g. in 2015, in Portugal 3.327 young people between 0-19 years had T1DM, which corresponds to 0.16% of the Portuguese population in this age group) and the common complications associated with DM may occur in early adulthood, at a time when different developmental tasks, namely those regarding sexuality, are occurring. Thus, living with T1DM during emerging adulthood and with its possible impact on emerging adults sexuality

(experienced or expected) is a situation that can be better understood by reconciling both a Developmental as well as a Health Psychology approach.

2.2. Theoretical Framing

Developmental Psychology authors have defined emerging adulthood as the transition period from adolescence to adulthood, between 18 and 30 years (Arnett, 2000). In terms of life span development, the transition periods represent distinct periods with unique biopsychosocial demands, which are characterized by the occurrence of complex and multidimensional marker events of life that produce an imbalance between stable periods of time and promote the acquisition of significant new skills and behaviors (Karlsson et al., 2008; Weissberg-Benchell, Wolpert & Anderson, 2007).

As a transition period, emerging adulthood is characterized by identity exploration, self-focus, freedom from parental supervision, acquisition of a maturing sense of identity, financial independence and establishment of stable intimate relationships with romantic partners, as well as assuming new roles in society (Arnett, 2000; Peters, Laffel & American Diabetes Association Transitions Working Group, 2011; Weissberg-Benchell et al., 2007). However, people with a chronic condition, such as T1DM, must meet additional demands related with the management of their disease (e.g. multiple daily insulin injections or infusion, monitoring of blood glucose levels, dietary control and regular practice of exercise) (Helgeson et al., 2007). During adolescence, glycemic control often deteriorates due to the hormonal changes associated with puberty, psychosocial problems and non-compliance behaviors (Helgeson et al., 2007; Peters et al., 2011), which may lead to the beginning of diabetes-related complications during emerging adulthood (Bryden et al., 2003).

According to the Common Sense Model of Self-regulation of health and illness (Leventhal, Brissette & Leventhal, 2003), a person's perceptions and representations of an illness and its management are based on their attribution and interpretation of a stimulus as well as their emotional and cognitive response to it, depending on their perceptions of severity and vulnerability. However, these perceptions and representations are not stable during the course of a chronic condition, once the emergence of new symptoms can change it (e.g. in case of T1DM, a hypo or hyperglycemic symptom or the beginning of related-complications) (Law et al., 2014; Petrie & Weinman, 2006).

Leventhal's model of self-regulation tells us that these perceptions of illness and its course are determinant for health related behaviors that can be beneficial for health, psychological well-being, adherence to therapy, the way one lives the disease and quality of life (Leventhal et al., 2003). Further, according to this paradigm the knowledge obtained with the analysis of the perceptions of illness also allows to evaluate health related behaviors and coping mechanisms to the illness or its symptoms (Law et al., 2014; Leventhal et al., 2003; Petrie & Weinman, 2006).

A conciliatory approach between Developmental and Health Psychology leads us to infer that many of the events that occur during emerging adulthood involve social environment transitions, such us becoming involved in more steady romantic relationships (Helgelson et al., 2015), which implies decisions about life plans (e.g. careers, studies and work) and about the romantic commitment (e.g. marriage, start a family and planning to have children) (Collins & van Dulmen, 2006; Shulman & Connolly, 2013). However, romantic relationships have received little attention in the area of chronic disease, especially T1DM (Helgelson et al., 2015).

2.3. Romantic Relationships among Emerging Adults with T1DM

In line with a normative progressive openness to new social contexts during this age frame, emerging adults with T1DM have to decide about how much they want to disclose and share about their chronic health condition in the context of new relationships as well as how much to involve partners in its care and management (Helgeson et al., 2015).

Comparing with their healthy peers, emerging adults with T1DM have to make a lot of daily decisions in terms of the management of their chronic disease, which may lead them to perceive the normative developmental changes that occur at this life stage and those related decisions as more complex and complicated (Bryden et al., 2001; Weissberg-Benchell et al., 2007). At this life stage, romantic peers develop a central role in T1DM emerging adults' health and well-being, which constitutes an important avenue of research (Monaghan, Helgeson & Wiebe, 2015). Romantic relationships as well as couple's plans and expectations can be affected by the demands of the daily management and by the emergence of T1DM related-complications that can interfere with one's sexual and reproductive health (Monaghan et al., 2015).

Although, emerging adults with T1DM identify the need of partners to know enough about diabetes to help them with symptoms of hyperglycemia and hypoglycemic and with the related self-management behaviors, some of them may be concerned about burdening romantic partners with these responsibilities (Monaghan et al., 2015). However, our review of the literature did not find information about how T1DM individuals self-disclose and communicate their disease or the content of that communications with their romantic partners.

Few studies have been developed about romantic relationships among emerging adults with T1DM. Jacobson et al. (1997), in a cross-sectional comparative study with 57

T1DM participants, found that they were equally likely to have a romantic partner as those without T1DM. However, compared to their healthy counterparts, those with T1DM seem to be more careful in their romantic relationships, once they reported less sense of friendship and less trust in this kind of relationships (Monaghan et al., 2015). Similarly, a longitudinal study developed by Maslow, Haydon, McRee, Ford and Halpern (2011) suggested that emerging adults with a chronic illness such as T1DM are just as likely to be married and have children as their healthy peers, and reported similar levels of relationship satisfaction. By contrast, a study developed by Seiffge-Krenke (1997) found that those with diabetes are less likely to develop a romantic relationship and more likely to do it later than those without diabetes.

A qualitative study developed by Sparud-Lundin, Öhrn and Danielson (2010), with a sample of 13 T1DM emerging adults, showed that they report the importance of the partners knowledge of the meaning of some symptoms (e.g., mood swings), which leads to partner's acceptance and reciprocally contributes to the experience of being loved and cared for by people with T1DM. Further, in some close romantic partnership, partners may take a more protective role that place additional burdens on T1DM emerging adults, interfering with the identity of being a couple and possibly challenging the meaning of the relationship (Sparud-Lundin et al., 2010). These findings lead researchers to believe that T1DM has the potential to interfere with romantic relationships, claiming that more research is necessary (Wiebe, Helgeson & Berg, 2016).

Recently, a quantitative study comparing 122 T1DM and 118 non-diabetic emerging adults regarding the impact of the conflict and support from their romantic partners as well as from their friends, found that romantic relationships are higher related with diabetes management and psychological well-being than friends relationships (Helgeson et al., 2015). Comparing with those without diabetes, emerging adults with

T1DM appear to be more affected by conflictual romantic relationships than to benefit from the supportive aspects of those relationships (Monaghan et al., 2015; Wiebe et al., 2016). Once it is expected that this kind of relationships have a higher level of investment, the development and functioning of romantic relationships might be affected by the complexity of the diabetes management regime (Helgeson et al., 2015).

2.4. Chronic Disease and Sexuality

Sexuality is an essential part of a healthy life (Byers & Rehman, 2014; Verschuren et al., 2010), which contributes to individual's personal and relational quality of life (George, Morris, Nguyen, Masters and Davis, 2014; McInnes, 2003; Verschuren et al., 2010). Therefore, sexuality is much more than sexual intercourse or the sum of people's erotic lives, it includes sex, gender identities, sexual orientation, eroticism intimacy, pleasure and reproduction (George et al., 2014; Glasier, Gülmezoglu, Schmid, Moreno & Van Look, 2006). That is why sexual health is not only the inexistence of a disease or dysfunction but a state of physical, emotional, mental, and social wellbeing that allows individuals to have a positive approach to sexuality and sexual relationships (Glasier et al., 2006). For individuals "with a chronic disease, sexuality is also a significant determinant of their quality of life, with sexual intimacy being an important mode of communication with their partners" (Clayton & Ramamuthy, 2008 cit in Verschuren et al., 2010, p.1).

Masters and Johnson framework (Basson, 2001), divided the physiology of the sexual response cycle in three stages (excitement, orgasm and resolution) dominated by different physiological reactions, meaning that an impairment in one of these phases can be due to a neurological, vascular or endocrine abnormality (Enzlin, Mathieu, Vanderschueren & Demyttenaere, 1998). However, human sexuality involves and is

mediated not only by biological aspects but also by psychological and relational factors that can affect sexual functioning and well-being in people with a chronic condition (Enzlin et al., 1998). Feelings of unattractiveness can affect the body image, concerns about social performance can have an impact in one's self-esteem and also interfere with individuals coping style and their global adjustment process (Goldsmith & Byers, 2016; Verschuren et al., 2010). Further, for individuals with a chronic disease it might be more difficult to stablish new romantic relationships because they may fear rejection and feel insecure about disclosing information related with their chronic health condition, which make them to redefine the characteristics they look for in a romantic partner (George et al., 2014).

The impact of a chronic disease on sexual function and sexual well-being also seems to be determined by the life stage at which the disease manifests itself (Verschuren et al., 2010). When a chronic disease appears before individuals become sexually active, it is expected that they take it into account as part of their sexual life and expectations (George et al., 2014; Verschuren et al., 2010), which seems to be the present case of T1DM, given its early diagnosis, usually during childhood and adolescence. On the other hand, for those who are confronted with a chronic disease at a later stage of life, when they already are sexually active, both the person and his or her partner will have to cope with the disease and its related implications on one's sexual functioning and well-being (Verschuren et al., 2010).

In this sense, besides the role that the emotional response that people have to their own chronic illness (Law et al., 2014; Leventhal et al., 2003), "the emotional reaction of a partner – either supportive or rejecting – to the diagnosis, treatment, process, and progress of a disease may influence both the psychological well-being of the patient and the relational functioning of the couple" (Verschuren et al., 2010, p.6). The association

between chronic physical illness and emerging adults sexuality (experienced or expected), specifically in the establishment of a new intimate or sexual relationship, is therefore important to understand especially at this life stage, when one of the most significant demands is the development of sexuality.

2.5. Sexual and Reproductive Health and T1DM

In long-term, a chronic hyperglycemic state can lead to T1DM complications, such as degenerative changes in small blood vessels or damage to peripheral and autonomic nerves (Boulton, et al., 2005; Brown et al., 2005; Verschuren et al., 2010; Ziaei-Rad, Vahdaninia & Montazeri, 2010) that may interfere with human's sexual and reproductive function (Basmatzou & Konstantinos Hatziveis, 2016; Enzlin, Mathieu, Van den Bruel, Vanderschueren & Demyttenaere, 2003; Kizilay, Gali & Serefoglu, 2017).

Researchers have been giving special attention to the DM impairments in males' sexual function, with several studies demonstrating that erectile dysfunction (ED) is the sexual problem with the highest prevalence among diabetic men (Nikolaidou, Nouris, Lazaridis, Sampanis & Doumas, 2015). Individuals with DM tend to develop ED within 10 years of diagnosis and comparing with non-diabetic men, it appears to be more severe during performance (Nikolaidou et al., 2015; Penson et al., 2003).

Additionally, problems with sexual desire, ejaculation and orgasm are also reported as direct and indirect consequences of the disease in men (Verschuren et al., 2010). At the reproductive level, studies with T1DM men (Vignera, Condorelli, Vicari, D'Agata & Calogero, 2012) reveal that their reproductive function may also be affected as a result of the effects of T1DM on the endocrine control of spermatogenesis, on the sperm's quality and in the mechanism of ejaculation (Agbaje et al., 2007; Basmatzou & Konstantinos Hatziveis, 2016). However, our literature review did not reveal any studies

that link these consequences to men's perceived doubts, fears or questions about their sexual and reproductive health.

Concerning women's sexual and reproductive health, several studies have confirmed that T1DM women have the same risk in developing sexual dysfunctions as men (Enzlin, Mathieu & Demytteanere, 2003; Enzlin, et. al., 2009), and also report higher prevalence of sexual dysfunctions than T2DM women and non-diabetic women (Doruk et al., 2005; Enzlin, Mathieu & Demytteanere, 2003; Enzlin et al., 2002). Several phases of the sexual response cycle of T1DM women seem to be affected by chronic hyperglycemia, and they may more frequently experience a decrease of sexual desire and arousal, involving slow or inadequate vaginal lubrication, dyspareunia during sexual intercourse and orgasm disorders (Enzlin et al., 2002; Nowosielski, Drosdzol, Sipiński, Kowalczyk & Skrzypulec, 2010; Rockliffe-Fidler & Kiemle, 2003).

In addition to these evidences, the etiology of sexual dysfunction in individuals with T1DM is not clear and its debate is still ongoing (Nowosielski et al., 2010). Based on empirical quantitative studies, researchers suggest that the etiology of sexual dysfunctions in T1DM men is linked to both organic (such as neuropathic complications of diabetes and metabolic control, leading to decreased receptivity to sexual stimuli and endothelial deregulation), and psychological factors (such as the presence of depressive symptoms, individual perception of sexual needs and partner-related factors) (Nowosielski et al., 2010). In women, sexual dysfunctions seems to be most strongly associated with psychological factors, such as depression, disease acceptance and emotional reactions, marital status, poor cognitive adjustment to diabetes and partner-related factors (Enzlin, Mathieu & Demytteanere, 2003; Enzlin, et al., 2009; Nowosielski et al., 2010; Rockliffe-Fidler & Kiemle, 2003).

T1DM woman's reproductive life can also be affected. This may be due to the hormonal disturbances that lead to complications in fallopian tubes, ovaries, uterus and menstrual disorders (e.g. premature menopause and delayed menarche) (Basmatzou & Konstantinos Hatziveis, 2016; Codner, Merino & Tena-Sempere, 2012). Delay menarche may occur due to a disturbance of the hypothalamic – pituitary – gonadal axis when T1DM is diagnosed in pre-pubertal age (Basmatzou & Konstantinos Hatziveis, 2016). These neuroendocrine effects can potentiate reproductive problems in some T1DM women and adolescents, leading to an increased risk of pregnancy-related problems, which include congenital abnormalities, perinatal death, neonatal hypoglycemia and spontaneous abortions (ADA, 2016; Griffiths, Lowe, Boardman, Ayre & Gadsby, 2008; Lavender et al., 2010). These adverse effects of T1DM on pregnancy seem to be significantly related with poor glycemic control in T1DM women (ADA, 2016; Griffiths et al., 2008; Temple, Aldridge & Greenwood, 2002).

However little is known about the issues around reproductive health from the T1DM woman's perspective and their knowledge about the care they must have and how it may affect them. A qualitative study developed by Lavender et al. (2010), with T1DM and T2DM pregnant women, showed that their concerns about potentially developing complications during pregnancy has an influence on their experiences, leading them to re-inforce the medical therapy of diabetes, which according to the authors reveal that women value their diabetes management and understand its importance to their well-being as well as their babies'.

Overall, our review of the literature shows that sexual and reproductive health have influence on individuals' well-being. However, T1DM individuals are at risk for both organic and psychogenic sexual dysfunctions (Enzlin, Mathieu, Van den Bruel et al., 2003; Lavender et al., 2010). Based on the cognitive approach to Health Psychology, the

psychological factors that can affect health, including sexual and reproductive health in T1DM individuals, are related with their perceptions and representations about the illness and its consequences (Law et al., 2014; Leventhal et al., 2003; Petrie & Weinman, 2006). Although T1DM has an impact in sexual reproductive health and considering that sexuality is an important developmental task in emerging adults, we did not find studies addressing sexuality in emerging adults with T1DM which represents a gap in the literature.

2.6. Current Study

The current study sets out to give a small but hopefully meaningful contribution about unexplored aspects of romantic relationships experiences and sexual and reproductive health of emerging adults with a T1DM diagnosis. To reach this goal, and in line with recent research methods for content elicitation with an emerging adulthood population (McCarrier, et. al., 2016), we developed an online qualitative exploratory survey with three open questions. The structure of the questions progresses from a more global approach to the topic questioning the existence, or not, of a specific experience of T1DM in emerging adults' intimate relationships, to narrow down until the identification of strategies used to face adversity in the context of sexual and reproductive health. More precisely, in line with the literature that highlights the impact of chronic illness in emerging adults romantic relationships, the first open question aims to shed some preliminary light on T1DM emerging adult's perceptions of the impact of T1DM in the formation of romantic bonds. In the second question we aimed at being more specific and address issues and doubts the participants have concerning sexual and reproductive health. Finally, the third question aims to explore experienced difficulties concerning sexual and reproductive health, as well as identifying the responses and strategies used to

manage these difficulties. Answering these questions may provide health professionals, advocates and the community with improved knowledge on the sexuality of emerging adults with T1DM.

3. METHOD

3.1. Participants

A total of 157 people gave informed consent to participate in the study and 98 individuals dropped out from the survey: 28 (28.57%) because they did not complete the survey, and 70 (71.43%) only completed the sociodemographic questionnaire.

The final sample involved 59 participants, 47 (79.66%) women and 12 men (20.34%). The mean participant age was 26,66 years (SD = 4,74) and the mean time since they have been diagnosed was 13,71 years (SD = 7,13, range 1 to 27) . There were 17 (28.81%) participants who reported to use insulin infusion pump and 42 (71.19%) use insulin pens for the daily management of the disease. Regarding sexual orientation, 54 (91.53%) self-identified as heterosexual, 2 (3.39%) as lesbian and 3 (5.08%) as bisexual women, with 58 (98.31%) participants claiming they had initiated their sexual life and 6 (10.17%) reporting to have 1 or more children. Regarding their relationship status, 13 (22.03%) were single, 43 (72.88%) participants were in a monogamous relationship and 3 (5.09%) participants in an open relationship. The sample was highly educated, with 37 (62.72%) having at least an undergraduate degree and 11 (18.64%) were current undergraduate college students; the remaining 11 (18.64%) participants had a high school degree. None of the participants reported to have sexual problems.

3.2. Procedure

The present research is part of a broader project about sexual health of emerging adults with T1DM, but this paper will only focuses on the analysis and interpretation of the qualitative data.

Following a participatory research approach (Cornwall & Jewkes, 1995), the study was discussed and set up with the support and contribution of the Portuguese Association

of Young People with Diabetes. The President of this association confirmed that an online survey would be the more adequate method for data collection, both due to the sensibility of the topic as well as their previous experience with emerging adults showing greater participation in forums and websites in comparison with face-to-face activities. After debating and sharing with the President of the association the main questions that could be a focus of interest, the researcher set up a draft of the survey. This received positive feedback from the association about the survey's suitability and adequacy to the needs discussed previously. After approval by the ethics committee of the Faculdade de Psicologia da Universidade de Lisboa, some T1DM emerging adults and collaborators known to the researcher piloted the full survey and evaluated the interface, visual display, length, and comprehensibility of the instructions and survey items until a final version of the survey was agreed upon.

To be included in the present study, participants had to (a) speak Portuguese; (b) be diagnosed with T1DM and (c) have between the minimum consent age of 18 and 35[2] years old.

We used a convenience sample, collected online between February and May 2017, using snowball like sampling methods. The advertising of the link was made in diabetes related pages in social networks (e.g. Portuguese Association of Young People with Diabetes and Youth Group of Portuguese Protective Association of Diabetics), inviting people to participate in the study. The participants were directed to the informed consent

[2] We increased the age range to 35 years old in order to be included as being an emerging adult. This results from our reflection and data appreciation. In Portugal, the age frame to achieve some of the maturational steps defined by Arnett (2000), such as leaving parents' home and have a first job, happens later than in other populations (http://brilliantmaps.com/europe-live-parents/; http://imgur.com/a/z1dP8#0; http://ec.europa.eu/eurostat/documents/3217494/6776245/KS-05-14-031-EN-N.pdf/18bee6f0-c181-457d-ba82-d77b314456b9; http://www.huffingtonpost.co.uk/2016/03/09/pregnancy-around-the-world-age-of-new-mums_n_9416064.html; https://www.eurofound.europa.eu/observatories/eurwork/articles/working-conditions-labour-market/portugal-young-peoples-transition-from-school-to-working-life). Therefore for the present study to be culture specific, we decided to propose a wider age range in the inclusion criteria.

page of the questionnaire, which had information concerning the nature and aims of the study, the names and positions of the researchers, anonymity and confidentiality (e.g., no personal information was collected that could identify the participants and no Internet Protocol (IP) was recorded), inclusion and exclusion criteria, the estimated time of the survey completion and the contact details for the researcher.

The participants initially completed a background questionnaire and a set of open questions followed by self-report measures on relevant dimensions. In the current study, the following open questions were analyzed: (1) "Do you consider that there are specific challenges that emerging adults with T1DM face when they start a romantic relationship with another person (e.g., boyfriend/girlfriend)? Which ones?"; (2) "What kind of questions and doubts regarding sexual and / or reproductive health do you consider to be specific of emerging adults with T1DM? (Provide examples if possible)" and (3) "Have you ever experienced any difficulties in your intimate, sexual or reproductive life related to T1DM? How did you deal with the situation?".

At the end of the survey, there was a final debriefing page including information on public resources (e.g., helplines) that participants could contact if they had experienced psychological or emotional distress during the completion of the survey.

3.3. Data Analyses

The storage, exploration, organization and analysis of the qualitative material was performed using the QSR NVivo Pro 11 software for Windows.

Our methodological approach to data analysis followed that of Braun & Clarke's thematic analysis (2006). This six-step method allows researchers to identify, analyze and describe how codes and patterns of meaning combine into broader themes, based on a flexible process (Braun & Clarke, 2006).

First, through reading and re-reading of the participants answers, it was possible to gain deeper familiarization of the data and identify emerging topics and dimensions. Further, an initial codification was made, allowing the classification of data in codes, which afterwards were combined and organized in subthemes, because they shared an underlying meaning, creating a primary system of categories. To finish this process of codification, the subthemes were organized in main themes that are less concrete and more global. The continuous process of codification, interpretation and re-codification of the data led to a final system of categories. The researcher identified and grouped individually the raw data responses into themes and subthemes. To ensure/increment the credibility and validity of the research, a triangulation by the researcher and the supervisor was made, in which, the supervisor checked for reliability and validity until a consensus and agreement was reached (Perluxo & Francisco, 2017), allowing the researcher to cross the results of the data analysis with the aims of the study.

For each open question, the thematic analysis of the participants' answers resulted in a set of themes, sub-themes and codes that were organized into three hierarchical systems, which can be found in Tables 1, 2 and 3. Some of the data items were coded simultaneously in different codes.

4. RESULTS

Concerning the exploratory nature of our study and our aims, even though there were a large number of participants who did not identify specific challenges or reported having experienced difficulties in their sexual and reproductive lives, almost all of them reported to have questions or doubts about these matters. We will report on the main results concerning each question separately.

4.1. Specific Challenges

Concerning our first open question: "Do you consider that there are specific challenges that emerging adults with T1DM face when they start a romantic relationship with another person (e.g., boyfriend/girlfriend)? Which ones?" many participants indicated that T1DM emerging adults are not faced with any specific challenges. Among those who reported specific challenges, the major themes we found were related to the *Interpersonal* and *Intrapersonal Impact* of T1DM (for a graphic representation of the relation between codes, subthemes and themes, see Figure 1).

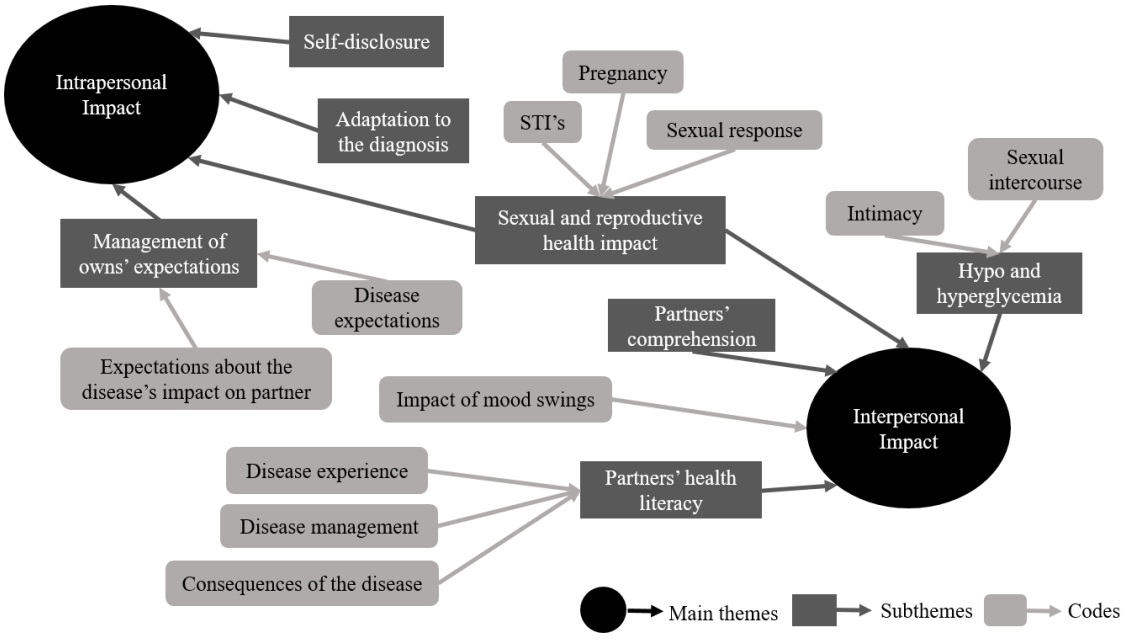

Figure 1. Thematic map of the answers to the first question

Intrapersonal Impact

Intrapersonal Impact was a main theme in which we included the answers that refer to an individual experience (see Table 1). These challenges may be related to the partner, but they are experienced individually and are not necessarily bound to having an ongoing relationship, or do not necessarily occur while in interaction with an intimate partner. For example, some participants referred inner difficulties about sharing information concerning the illness, referring to the personal emotional experience associated with disclosure, as well as the process of choosing the right moment or time to disclose their clinical condition. Even though this is a challenge related to an interpersonal context, the participants highlight the impact the experience has on themselves. Another subtheme is the *adaptation to the diagnosis*. This subtheme aggregates answers with a patterned reference to the fears and concerns about the personal adaptation to diagnosis, when a personal understanding and emotional experience is happening that could in turn impact their social and intimate life. Another subtheme referred by some participants refers to the *management of owns' expectations*, including personal expectations regarding the disease and expectations regarding the disease's impact on the partner.

Interpersonal Impact

We included the answers that refer to a shared experience that can affect T1DM emerging adults, and influence their partners and the romantic relationship, in the main theme *Interpersonal Impact* (see Table 1). These challenges occur while in interaction with an intimate partner. For example, the majority of participants referred perception of the *partners' comprehension* as a specific challenge, referring the bidirectional influence between the relationship and the illness: the illness has an impact on the relationship, but the relationship itself also impacts the management and experience of the disease.

Another subtheme referred by many participants refers to the *partner's health literacy*, including the knowledge of the partner about the illness experience, management and consequences and the impact it has on T1DM emerging adults in some situations, such as the management and awareness on the occurrence of hyper or hypoglycemia which is, in turn another subtheme. This subtheme, *hypo and hyperglycemia*, reflects the participants' highlight of the management of these situations as a challenge during sexual intercourse and/or in intimacy. The *impact of mood swings* associated with the clinical condition was also a challenge frequently reported.

Even though these major themes (*Interpersonal* and *Intrapersonal Impact*) are presented separately, they were regularly referred by participants as interconnected. This interconnectedness is demonstrated by the existence of the shared subtheme *sexual and reproductive health impact*. This subtheme aggregates answers with a patterned reference to concerns related with becoming and being pregnant, the possibility of developing Sexual Transmitted Infections (STI's) and difficulties related with the sexual response.

Table 1.

Description of themes, subthemes, and codes including example answers found in answers to the first question

Main Themes (Third Level)	**Sub-themes (Second Level)**	**Codes (First Level)**	**Description**	**Examples**
Intrapersonal Impact	Adaptation to the diagnosis		Adaptation (e.g. fears and concerns) to the initial phase of the diagnosis	*- The biggest challenge is learning how to deal with the disease.* *- No one is prepared to receive the news of an illness that is "forever."*
	Self-disclosure		Sharing information about the disease and / or its management	*- I think it is necessary to explain T1DM to our partner, which can be difficult.* *- There is always fear of telling ...* *- It is a sensitive subject and it can be difficult to talk about it.*
	Management of owns' expectations	Disease expectations	Management of owns' expectations concerned to the illness and / or its management	*- The challenge of living a life the more similar as possible to my boyfriend's and that he doesn't stop doing or eating things in front of me just because I can't.* *- Will I be accepted?*
		Expectations about the disease's impact on partner	Management of owns' expectations about the illness's and / or its management impact may have on partner	*- It was complicated to manage my expectations regarding the other and what he might think ...* *- There is always fear of telling ... will it change anything, will he abandon me?*
Interpersonal Impact		Impact of mood swings	Mood swings as a specific challenge	*- The mood swings due to the change of glucose levels can influence a relationship.* *- There are young people who fear that their partner might not understand the changes of humor…*

Partners' comprehension		Partner's understanding / acceptance which evidences the bi-directionality between the relationship and the disease	*- The challenge of understanding that the relation may not go as expected.* *- The partners' misunderstanding. You only realize what it is to have a disease when you have it.* *- The important thing is to be understanding with each other.*
Hypo and Hyperglycemia	Sexual intercourse	Management of hypo and/or hyperglycemia immediately before, during and immediately after sexual intercourse	*- The possibility of having hypoglycemia during sex.* *- I'm basically doing unplanned exercise, which sometimes implies having hypoglycemia immediately after.*
	Intimacy	Management of hypo and/or hyperglycemia in the context of romantic relationships intimacy	*- If you wake up next to the person and want to do what you want, you can't do it without first confirming the glucose levels...* *- The simple fact of going out eating and have to take tables for counting hydrates is an example of a dating challenge.*
Partners' health literacy	Disease experience	Partners' health literacy about the disease and the experience of living with it	*- The partner should be aware of what diabetes is.* *- To convey and understand what it's like to live with diabetes.* *- It's necessary to explain DM to our partner which can be difficult.*
	Disease management	Partners' knowledge to support and assist in the disease management, including the knowledge about what needs to be done in emergency situations	*- We use a lot of equipment that the boyfriend needs to know and become familiar with as well as the symptoms of hypo and hyper and what to do in those situations.*

				- The person at our side has to deal with the disease as well as we do, and know how to act in an emergency.
		Consequences of the disease	Partners' health literacy about the consequences and implications of the disease (e.g. mood swings, bruising from injections)	*- The boyfriend must be aware of the disease and its consequences.* *- The partner has to be prepared to deal with the good and bad moments.* *- Having bruises around the legs and belly may not be pleasant to the eyes for recent partners who don't know what DM is (...)*
(Shared Subthemes)	Sexual and reproductive health impact	Pregnancy	The entire pregnancy process	*- Before getting pregnant it's necessary to make a treatment, that's why you have to be very careful in the sexual act so that an unwanted pregnancy doesn't happen.*
		Sexual response	Sexual dysfunctions (e.g. erectile dysfunction, lubrication difficulties)	*- The difficulty of lubrication due to the variation of glucose levels.* *- Sexual intercourse and in the case of women, vaginal dryness and in men, impotence.*
		STI's	Higher probability of contracting STIs	*- We are more susceptible to have a sexually transmitted disease.*

4.2. Questions and Doubts about Sexual and/or Reproductive Life

When we analyzed the data concerning our second open question "What kind of questions and doubts regarding sexual and / or reproductive health do you consider to be specific of emerging adults with T1DM? (Provide examples if possible)", a minority of the participants reported to have no questions or doubts about their sexual and/or reproductive life. Among the majority who reported to have questions and doubts, we found three major themes: *Sexual Response*, *Metabolism* and *Planning a Family* (for a graphic representation of the relation between codes, subthemes and themes, see Figure 2).

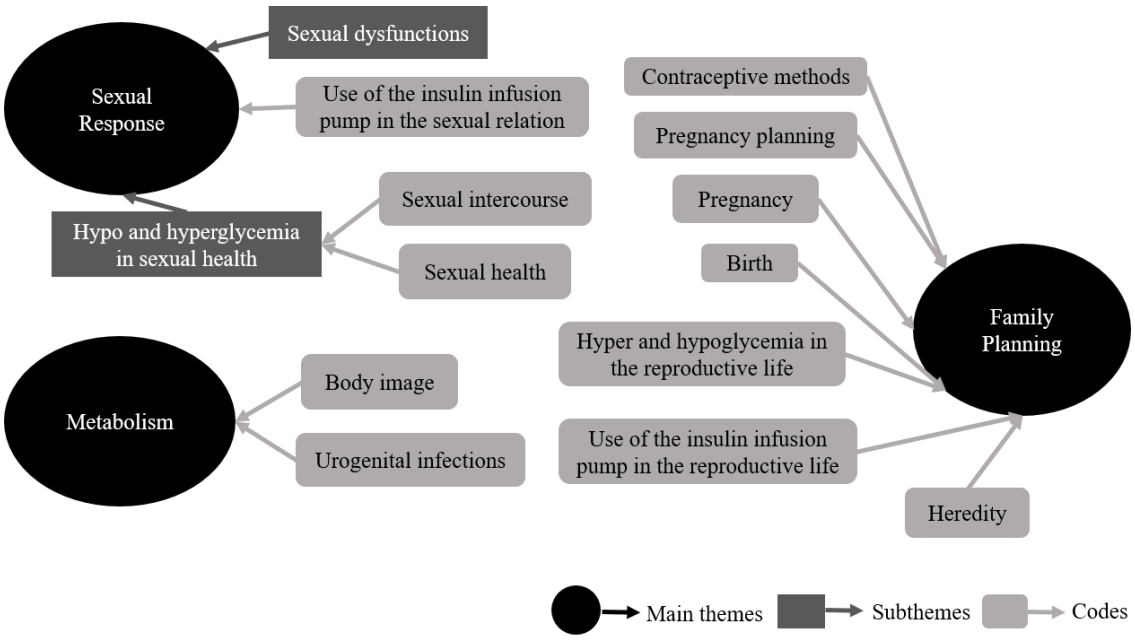

Figure 2. Thematic map of the answers to the second question

Sexual Response

Sexual Response was a main theme in which we included answers that refer to questions and doubts about the impact of the illness and treatment in the sexual response (e.g., erection) of T1DM emerging adults. In this context, a subtheme mentioned by many participants referred questions and doubts about having *hypo or hypoglycemia*, especially

during sexual intercourse. Another subtheme refers to the possibility of the development of *sexual dysfunctions* and how to deal with them (see Table 2 for examples). Finally, a number of participants reported concerns about the use of the insulin infusion pump in a sexual relationship, referring doubts about how to manage it during sexual interaction.

Metabolism

Metabolism was a main theme in which we included the answers that refer to questions or doubts related with the organism' metabolic response to the disease, its consequences and/or its treatment. Although only a few number of participants mentioned questions or doubts related with this main theme, the ones that did it, reported questions about the possibility of developing urogenital infections and concerns about how to deal with these, as well as concerns about the impact of T1DM treatment on body image, especially body weight (see Table 2 for examples).

Family Planning

In this main theme, we aggregated the answers referring to questions or doubts about the whole process of planning to have a child, since pre-conception until birth. The majority of participants reported questions or doubts about pregnancy planning, pregnancy and heredity (see Table 2 for examples). In contrast, a few participants mentioned questions or doubts about birth, use of the insulin infusion pump during pregnancy and hypo or hyperglycemia through reproductive life.

Table 2.

Description of themes, subthemes, and codes including example answers found in answers to the second question

Main Themes (Third Level)	**Sub-themes (Second Level)**	**Codes (First Level)**	**Description**	**Examples**
Sexual Response	Hypo and hyperglycemia in sexual health	Sexual intercourse	Hyper and/or hypoglycemia immediately before, during and immediately after the sexual intercourse	*- With hyperglycemia or hypoglycemia, can I have sex?* *- What if you get hypoglycemia during sex?* *- How to prevent hypoglycemia (that breaks the moment) during sex?*
		Sexual health	Occurrence of hyper and/or hypoglycemia in sexual life	*- Will the values change greatly?* *- How can diabetes interfere with my sex life, beyond hypoglycemia and hyperglycemia?*
	Sexual dysfunctions		Changes in the sexual response cycle (e.g. erection, orgasm, pain, ...)	*- How to deal with body changes resulting from diabetes such as vaginal dryness or impotence?* *- Vaginal dryness, decreased libido?*
		Use of the insulin infusion pump in the sexual relation	Management of the use of the insulin infusion pump in sexual relations	*- How will it be to have relations with the insulin pump? Does the cord wind up everywhere? Is it uncomfortable?* *- What to do with the insulin pump (remove? give insulin?)*
Metabolism		Body image	Body image changes	*- Does insulin make you fat?* *- If I do not give insulin, will I lose weight?*
		Urogenital infections	Urogenital tract infections	*- Sometimes I have vaginal candidiasis; I was told it was common in diabetic women.*

			- Does hyperglycemia cause more infections in women? *- How to avoid / minimize infections in the case of women since they increase significantly with diabetes.*
Family Planning	Contraceptive methods	Use of contraceptive methods and its implications	*- Does diabetes interfere with contraceptive methods?* *- Does the pill change your blood sugar levels?*
	Pregnancy planning	Possibility of getting pregnant and the procedures necessary for fertilization and pregnancy planning	*- Can I have children?* *- What glycemic reference levels are advised before and during pregnancy?* *- Can I get pregnant without treatment?*
	Pregnancy	Disease and its management throughout the pregnancy process	*- Will my glycemic levels affect my children during pregnancy?* *- Should pregnancy be monitored from the start? That is, fully programmed?*
	Birth	Moment of birth	*- Can a T1DM woman have a normal childbirth?* *- Doubts in the stage of pregnancy, from planning to birth.*
	Hypo and hyperglycinemia in reproductive life	Variation of glycemic levels in different stages of reproductive life	*- What glycemic reference levels are advised before and during pregnancy?* *- Can uncontrolled glycaemia lead to embryonic / fetal development complications?*

Heredity	Possibility of generational transmission	*- What is the risk / percentage of my future child to have T1DM?* *- Which risks will there be for the baby?*

4.3. Experienced Difficulties in Sexual and/or Reproductive Life and Ways to Deal With Them

Concerning our last open question: "Have you ever experienced any difficulties in your intimate, sexual or reproductive life related to T1DM? How did you deal with the situation?", many participants indicated they had not experienced any difficulties in their sexual and/or reproductive lives. Among those who reported difficulties, the major themes we found were related to *Negative Emotionality*, *Urogenital and Reproductive Life*, *Sexual Activity* and *Response to Difficulties* (for a graphic representation of the relation between themes, subthemes, and themes, see Figure 3).

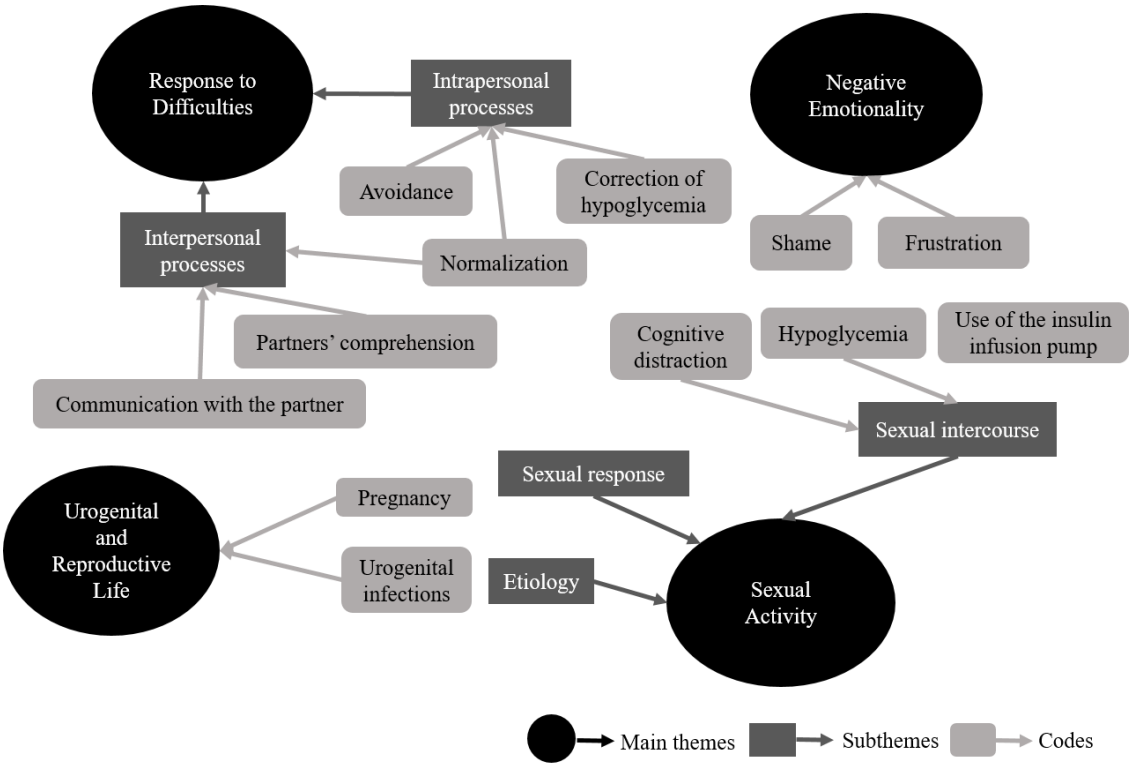

Figure 3. Thematic map of the answers to the third question

Negative Emotionality

Negative Emotionality was a main theme in which we included all the answers that refer to a negative emotional experience, such as shame and/or frustration concerning

T1DM emerging adults' sexual and / or reproductive lives (see Table 3 for examples). The majority of the expressed negative emotional experiences were interrelated with other experienced difficulties that were grouped under the main theme of *Sexual Activity* (e.g., *"it's terrible and frustrating to stop the sexual intercourse to take care of my glycose levels"*).

Urogenital and Reproductive Life

We included in this main theme all the answers that refer to experienced difficulties involving the impact of the illness and its treatments in the urogenital tract (e.g., the development of urinary infections) and in the reproductive life, namely difficulties related with becoming pregnant (see Table 3 for examples).

Sexual Activity

Under this main theme we included answers that reflect difficulties specific to *Sexual Activity*. For example, many participants referred the emergence of thoughts regarding doubts and concerns whether or not the experience of sexual difficulties could be explained by the diagnosis of T1DM, a concern we grouped under the subtheme *etiology*. *Sexual response* is another subtheme that aggregates answers with a patterned reference to the experience of difficulties and impairments in sexual response (see Table 3 for more examples). Another subtheme referred by the majority of participants refers to the experience of difficulties during *sexual intercourse* (see Table 3 for specific examples).

Response to Difficulties

Response to Difficulties was a main theme in which we included the ways, strategies and responses reported to use, to face the experienced difficulties in their sexual and/or reproductive life, especially in their sexual life as difficulties in sexual activity were the most often reported. Among those who reported strategies and responses to the experienced difficulties, we found two subthemes related to *intrapersonal* and *interpersonal processes*. The subtheme *intrapersonal processes* aggregates answers associated with individual behavioral (e.g., avoidance) and instrumental (e.g., correction of hypoglycemia) responses and strategies to deal with the experienced difficulties. On the other hand, the subtheme *interpersonal processes* includes strategies to deal with the experienced difficulties that are directed at or involve the other person (e.g., communication with the partner) (see Table 3). Even though these subthemes - *inter* and *intrapersonal processes* - are presented separately, they are sometimes referred by participants as interconnected. This interconnectedness is demonstrated by the existence of the shared code normalization, which is coded both in *intra* as well as *interpersonal process*. Under this code, participants highlight the importance of their own strategies and responses as well as the partners' support in a dyadic context.

Table 3.

Description of themes, subthemes, and codes including example answers found in answers to the third question

Main Themes (Third Level)	**Sub-themes (Second Level)**	**Codes (First Level)**	**Description**	**Examples**
Sexual Activity	Sexual intercourse	Hypoglycemia	Occurrence of hypoglycemia immediately before, during and/or immediately after sexual intercourse	*- Sometimes it happens that there is the need to stop the intercourse because of hypoglycemia.* *- It already happened to have hypoglycemia during sexual intercourse.*
		Cognitive distraction	Rumination and concerns with the interference of the disease and/or its management during sexual intercourse	*- Sometimes I can't help thinking about Diabetes and I have recurrent thoughts about the possibility that glucose levels aren't adapted to the practice and so I don't totally focus on the sexual relation, especially on the preliminaries ...*
		Use of the insulin infusion pump	Insulin infusion pump management difficulties during sexual intercourse	*- There is some caution that we need to have with the pump* *- I was ashamed to show my body with the cannula.* *- Hyperglycemia because the cannula of the insulin pump blocked the flow and remained 2h without insulin*
	Sexual response		Phases of the sexual response cycle (e.g. desire, pain, orgasm, excitement, erection, …)	*- I have been feeling difficulties in having an orgasm* *- In a few situations I had more difficulty in having an erection* *- Vaginal dryness, decreased libido.*
	Etiology		Doubts regarding the experienced difficulties to be or not derived from disease	*- I can't establish a direct cause-effect relationship between this fact and diabetes.* *- It happened but I don't know if it's because of diabetes.*

				- I do not know if it is associated with taking the pill or if it's really my organism / disease.
Urogenital and Reproductive Life		Pregnancy	Difficulties during the pregnancy process (e.g. conception difficulties, metabolic control…)	*- Having difficulties in getting pregnant and the tight control of diabetes during the gestation period.*
		Urogenital infections	Difficulties at urogenital infections level (e.g. urinary infections, candidiasis...)	*- To have infections.* *- The various infections to which we are susceptible.*
Negative Emotionality		Shame	Discomfort and/or inhibition associated with the disease and its implications	*- Shame* *- I was ashamed to show my body with the cannula.*
		Frustration	Difficulties in managing the disease and its chronicity.	*- It is difficult and frustrating* *- Stopping everything to take sugar is terrible.* *- It's annoying ... for me and for my partner too.*
Response to Difficulties	Intrapersonal processes	Correction of hypoglycemia	Correction of hypoglycemia during the sexual intercourse, as an instrumental response to the experienced difficulties.	*- We stopped and I corrected it.* *- Stop the act, correct the levels and continue.* *- Interrupt to correct it ... and then return to the point where we were.*
		Avoidance	Absence or diminution of the sexual activity regularity to deal with the experienced difficulties in this area	*- As much as I don't want to, I avoid to not fall into the same problem all the time ...*
		Normalization	Normalization of the experienced difficulties at sexual and reproductive health level, by their own	*- I have confidence enough to deal with this type of situation naturally and even making fun of it.* *- It happened in very few situations and I dealt normally with it and I managed to solve it.*
	Interpersonal Processes	Partners' comprehension	Partner's understanding of sexual and reproductive health difficulties	*- It isn't a problem…my boyfriend understands perfectly.*

		- *My partner understood and supported me.* - *With support from my partner.*
Communication with the partner	Use of communication (e.g. dialogue and psychoeducation) as a strategy to prevent or deal with experienced difficulties at sexual and/or reproductive health level	- *I always tried to talk about it.* - *Try to demystify taboos.* - *Through dialogue with my partner.* - *I explained the situation to the person with who I was.*
Normalization	Normalization of the experienced difficulties at sexual and reproductive level, through interaction with the partner.	- *The understanding by the other is immediate by the empathy to pass through the same (...) simplify is the key.* - *Naturally ... my partner already knew and didn't mind.*

5. DISCUSSION

The current study set out to explore aspects of intimate romantic relationships and of the sexual and reproductive health of emerging adults with a T1DM diagnosis. More precisely, it aimed at identifying T1DM emerging adult's perceptions of the impact of the disease in their romantic relationships, their specific concerns and experienced difficulties concerning sexual and/or reproductive health, as well as their responses to deal with these possible experienced difficulties.

A number of respondents did not identify any specific challenge in their sexual and reproductive lives. This may be explained by the individual's perceptions of their illness which may determine their emotional or cognitive response to it (Law et al., 2014; Leventhal et al., 2003; Petrie & Weinman, 2006). More precisely, in the early stages of a chronic condition diagnosis, such as in emerging adults with T1DM, there may be a display of personal crises that can be linked to the experience of grief (Nash, 2014), which in turn can possibly lead to denial of the disease and/or its symptoms, such as the ones related with sexual and reproductive health. Some participants have not identified any experienced difficulties concerning their sexual and/or reproductive life. This result might also be explained by the sample characteristics, once some of the participants did not yet initiated their reproductive life or may not have made decisions about starting a family (Collins & van Dulmen, 2006; Shulman & Connolly, 2013). Additionally, diabetes long-term complications tend to manifest 5 or 10 years after the diagnosis (Ziaei-Rad et al., 2010). In the current sample there were some participants with a diagnosis of less than 10 years, who may not yet experienced long-term complications. Another possible explanation for this result can be the participants' lack of knowledge and awareness of diabetes related complications concerning sexual and reproductive life. This might be due to an absence of discussions regarding the topic of emerging adults' sexual and

reproductive health in clinical settings. This may be explained by an abrupt transition between pediatric and adult care, often associated with missing of the medical appointments (Weissberg-Benchell et al., 2007). This is a key period for sexuality development when professionals should discuss sexual and reproductive health, but often do not do so.

Despite the fact that some participants reported no challenges, doubts and/or experienced difficulties in sexual and reproductive health, taken together the answers to the three open questions reflect that most emerging adults with T1DM have unique perceptions, expectancies, doubts and experiences about their romantic life and sexual health that are illness related. This result is theoretically in line with the idea that chronic disease has an impact both on individuals' physical condition and on psychological well-being, directly or indirectly leading to consequences on sexual function and well-being (McInnes, 2003; Verschuren et al., 2010). Moreover, the way that both the person and his/her partner may experience and perceive the disease and its consequences determines the reactions and responses to a possible impairment (Verschuren et al., 2010). From a life-span approach, at this life stage emerging adults start to be involve in steady romantic relationships, in the context of which they usually take decisions about future life plans (Collins & van Dulmen, 2006; Helgelson et al., 2015; Shulman & Connolly, 2013). Even though our results are theoretically grounded and expected, to our knowledge they are unique as the existing literature had not previously established that there is a specific set of expectations, doubts and experiences concerning the sexual health of T1DM emerging adults.

Concerning our first open question: "Do you consider that there are specific challenges that emerging adults with T1DM face when they start a romantic relationship with another person (e.g., boyfriend/girlfriend)? Which ones?", the main themes

(*Intrapersonal* and *Interpersonal Impact*) are interrelated and reflect a movement between the individual and interpersonal impact of the disease. This result is supported by literature that highlights the challenges and demands that emerging adults face in an intrapersonal level regarding their disease, its management and consequences (Helgeson et al., 2007; Peters et al., 2011; Wiebe et al., 2016). It is also in line with other knowledge that highlights that the daily related decisions and challenges imposed by T1DM in social contexts, such as romantic relationships (Helgeson et al., 2015) can interfere with the couple's plans and expectations, demanding its redefinition (Monaghan et al., 2015).

Within this major theme, *adaptation to the diagnosis* also emerge as a specific challenge reported, which is consistent with the literature on chronic illness that refers that the adaptation process to a chronic condition is a dynamic process with significant physical, emotional and identity challenges (Smedema, Bakken-Gillen & Dalton, 2009). The way each person perceives these challenges and responds to them will determine the process of adaptation and affect his or her well-being (Leventhal et al., 2003; Smedema et al., 2009). Romantic relationships' wellbeing can also be affected by this process, once individuals' health may bidirectional influence and be influenced by their partners (Reed, Butler & Kenny, 2013) and as such the process of adaptation to the diagnosis of T1DM and its challenges should be read in light of the context of each person's life (Verschuren et al., 2010).

The most reported challenge concerns *self-disclosure* about their chronic health condition and the *management of owns' expectations* related to the disease as well as the person's own expectations about the disease's impact on their partners. Existing research has stated that when establishing romantic relationships, T1DM emerging adults may worry about how partners will react to their disease and its related-implications, namely it management and consequences, which leads them to have to decide how or if they want

that their partner have an active role in the care of the disease (Monaghan et al., 2015). Although, they worry about *self-disclosure* (an interpersonal aspect), they also identify the need of partners to know enough about diabetes to help with symptoms of hypoglycemic and hyperglycemia (*partners' health literacy*, an interpersonal aspect). These findings are in line with previous research that highlighted that disclosure of one's illness status is a focus of concern (Monaghan et al., 2015).

Regarding the *Interpersonal Impact*, participants often report that *partners' comprehension* and *health literacy* about T1DM (e.g., management and possible consequences) leads to their acceptance of the chronically ill person. This is consistent with Sparud-Lundin et al.,' study (2010) that found that the partners' awareness of T1DM symptoms contributes to the T1DM individuals' feeling of being loved and cared for.

The answers to the first open question reveal two other subthemes that are viewed as challenges. One is *hypo and hyperglycemia* in intimacy and sexual intercourse. This finding is consistent with Basson, Rucker, Laird and Conry (2001) as well as Rockliffe-Fidler and Kiemle (2003) studies that identified more concerns among T1DM woman with the possibility of becoming hypoglycemic during sexual activity, than those with T2DM. The other subtheme referred to is the challenges about *sexual and reproductive health*. Our findings are preliminary, but still suggest that the management of the disease in sexual contexts and the challenges of sexual health are a focus of concern for emerging adults with T1DM. On one hand, this result points out that health professionals should consider these topics as a focus of assessment and/or psychoeducation (Mock, Kurtz & Mamet, 2008).

Regarding the second aim of the study, and the open question associated "What kind of questions and doubts regarding sexual and / or reproductive health do you consider to be specific of emerging adults with T1DM? (Provide examples if possible)",

we found that most questions and doubts were related to *Sexual Response* and *Family Planning*.

The doubts presented show that all steps of *Family Planning* are a focus of questions and/or doubts, which can lead us to infer that T1DM emerging adults are aware of the possible consequences and complications of the disease to their reproductive life and as so, they want to be informed before taking the important step of starting family planning. In comparison to the first question where reproductive health was not frequently referred, in this open question participants presented doubts regarding different aspects of reproductive health (e.g. contraceptive methods, pregnancy planning, birth, heredity). This might be explained by the characteristics of the sample, since only 10,17% reported to already have one or more children and most of the others might be anticipating their future reproductive life (Shulman & Connolly, 2013; Collins & van Dulmen, 2006). These concerns are consistent with current knowledge about T1DM complications, which shows that sexual (Enzlin et al., 2002; Nowsielsky et al., 2010; Penson et al., 2003; Verschuren et al., 2010) and reproductive function (Agbaje et al., 2007; Basmatzou & Konstantinos Hatziveis, 2016; Griffiths et al., 2008; Lavender et al., 2010) can be affected as a related-complication of T1DM. Therefore, the address and clarification of these issues are a necessary feature in the clinical approach to this population.

Under the main theme *Metabolism,* we found doubts regarding the influence of insulin in body weight that can be explained by the perceived importance of the body image impact among emerging adults (Goldsmith & Byers, 2016), which in some extreme cases can be associated to eating disorders, such as "diabulimia" in T1DM individuals (Francisco & Falcão, 2017). Further, this result can also possibly be associated to beliefs regarding the effects of insulin administration, based on available information about this topic (DCCT Research Group, 2001; Russel-Jones & Khan, 2007). The other field of

questioning, urinary infections, reveals a doubt that is sustained by the literature that demonstrates that there is more vulnerability to this type of infections among T1DM individuals (Brown et al., 2005). This result on one hand suggest that participants are aware of the impact of T1DM on their health, but also reveal that they have doubts that need to be clarified. There are no other studies that have addressed the voiced concerns of emerging adults with T1DM about sexual and reproductive health, however the current results clearly state that this is a focus of interest of these participants that cannot be overlooked.

Concerning our third and last question "Have you ever experienced any difficulties in your intimate, sexual or reproductive life related to T1DM? How did you deal with the situation?", the difficulties reported were not circumscribed to *Sexual Activity*. Participants expressed a set of concerns that go beyond that and voiced cognitive and emotional processes associated with their experience of difficulties. One possible explanation for these findings is that the way that individuals perceive and cognitively represent their experienced difficulties will determine their cognitive and emotional response to it (Law et al., 2014; Leventhal et al., 2003; Petrie & Weinman, 2006), which can have an effect in one's sexual response (Nowosielski et al., 2010). This is consistent with cognitive emotional models of sexual response, which highlight that the sexual response is explained by a set of factors that occur during sexual activity (e.g., cognitive distraction during sexual activity) (Pascoal, Narciso & Pereira, 2012) but also by cognitive factors shared by men and women that occur outside the context of sexual activity (e.g., sexual beliefs) (Pascoal, Alvarez, Pereira & Nobre, 2017).

Even though less frequently, participants experienced difficulties related to the reproductive life and to the urogenital tract, more precisely the experience of difficulties in pregnancy and in the development of urogenital infections respectively, which is

sustained by the literature that demonstrates that there are more vulnerability to have urogenital infections among T1DM individuals (Brown et al., 2005).

In addition to these findings, it seems that T1DM emerging adults tend to resort to a set of available responses to face these difficulties. Some of these have a more instrumental adaptive component (e.g. hypoglycemia correction). However, the psychological processes identified (e.g., avoidance), can on one hand be an adaptive strategy to protect T1DM emerging adults from situations in which they do not perceive support or which they perceive as hostile (e.g. anticipated rejection), but on the other hand, may prevent them from acquiring other adaptive strategies (e.g., communication). Further, the results also highlight the importance of the partner's communication skills, demonstration of comprehension, acceptance and support as fundamental to help T1DM emerging adults.

Looking at the results as a whole, in this sample, romantic life and sexual and reproductive health are a rich source of challenges, doubts and experiences for emerging adults with T1DM. In this preliminary study, some new areas were identified as crucial. *Hypoglycemia and hyperglycemia* in sexual activity, especially during sexual intercourse, emerge as a relevant theme across the three questions examined and it also appeared associated to specific response strategies. This knowledge could be incorporated in psychoeducational contexts (e.g., clinical practice, portals and social advocacy groups). Another new result identified regarded use of the insulin infusion pump in the context of sexual activity and during pregnancy. This can be explained by the daily requirements of the management of T1DM (Wiebe et al., 2016) increased by the need to manage and understand this new therapeutic methodology and its individual and relationship management and understanding.

Although our study aimed to be exploratory, there are several limitations that cannot be overlooked. The major methodological shortcoming was that the application of the questionnaire online, so that we could not explore and deepen the meanings of particular participants' answers. Moreover, the study is nation specific and as such, reflects the meanings of Portuguese emerging adults with T1DM diagnosis, which can be partially influenced by the national healthcare services characteristics. In this sense, an adaptation of this study to other populations where different approach to T1DM management are available may lead to different results.

In future research, it would be useful to do a comparative study between individuals' who already had and had not initiated an active sexual life. It would also be important to investigate the meanings and perceptions in a higher age-range. Moreover, it might be also important to explore the health professionals' and partners' perceptions and representations about sexual and reproductive health of T1DM emerging adults.

This study has implications at clinical, social, educational and research levels. It highlights that both sexual and reproductive life are important issues for emerging adults with T1DM to be approached in clinical settings as well as in social contexts, such as schools, universities or support groups. Further, this investigation suggests that in order to respond to the participants' needs, sexuality should be part of the training of health professionals in Portugal, a finding demonstrated by other studies (Alarcão et al., 2012). In the same sense, professionals in the area of Clinical Sexology and Sexual Medicine may need training in Health Psychology, in order to better understand and respond to the multidisciplinary needs of T1DM emerging adults (Alarcão, Ribeiro, Almeida & Giami, 2017). Our results also have implications for research as this set of findings establish the influence of romantic relationships in promoting theirs partners' health and well-being

and support the claim for dyadic designs in health research to investigate intra and interpersonal mechanisms of health and well-being (Reed et al., 2013).

In summary, this study take into account that sexual and reproductive life is an area of interest voiced by emerging adults with T1DM and highlights the need to go deepen in the illness related Health Psychology research, integrating sexual and reproductive health in its models of the disease impact (Verschuren et al., 2010).

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